Public Health and Preventive Medicine

HIV Disease Prevention and Treatment

A Model for Local Planning

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This is one of a series of articles from western public health departments.

Since first reported in 1981, about a fourth of all cases of the acquired immunodeficiency syndrome in the United States have occurred in California. In response to the human immunodeficiency virus (HIV) epidemic, California has developed a five-point strategy consisting of epidemiologic surveillance; prevention education; the provision of medical treatment and supportive services; research; and continuous planning, evaluation, and coordination of programs. Given the size and tremendous environmental and cultural diversity of California, as well as the variable local impact of HIV disease, local jurisdictions need to develop HIV disease prevention and treatment plans specifically tailored to the circumstances of their communities. At a minimum, these plans should include central participatory planning, epidemiologic surveillance, HIV antibody testing and prevention education programs, provision for medical treatment and social support services, and coordination of financing mechanisms. We present a model for such plans.

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Since the acquired immunodeficiency syndrome (AIDS) was first reported in 1981, about a fourth of all cases in the United States have occurred in California. As of June 30, 1988, a total of 14,414 cases had been reported to the California Department of Health Services (CDHS). Of these persons, 8,378 (58%) have died.

The CDHS projects that another 35,000 cases of AIDS will occur in California by the end of 1991. It is also estimated that more than 300,000 people in California currently are infected with the human immunodeficiency virus (HIV), the causative agent of AIDS.

Based on our current understanding of the natural history of HIV infection, it must be assumed, for purposes of planning, that HIV-related illness will develop in all persons infected with the virus, and fulminant AIDS, or end-stage HIV disease, will develop in about half of these persons. Further, in the absence of a preventive vaccine, disease-arresting immunotherapy, or cure, and with none imminent, we must assume that AIDS is uniformly fatal. Education and other public health interventions continue to be the primary means of combating the HIV epidemic.

In addition to concern among the public health and medical communities, HIV disease continues to be among the top sociopolitical issues of the day, as reflected in recent public opinion polls and the nearly 150 AIDS-related pieces of legislation introduced in the California legislature in 1988. This is nearly three times more than were introduced in 1987.

It is within this context that the California Department of Health Services has prepared a document to assist local jurisdictions plan for HIV disease.[1] We think all local health departments should have a plan for the prevention and treatment of HIV disease, consistent with overall state plans and policies. We have adapted this CDHS planning document for presentation here because health care practitioners need to actively participate in the community response to the HIV epidemic. To be effective, though, they must understand the framework in which they are operating.

Factors Affecting California's Planning for HIV Disease

In the past three years, the California Department of Health Services has expended considerable effort in planning its response to the HIV epidemic and has promulgated a number of reports relating to AIDS.[1-3]

Throughout the epidemic, statewide planning for HIV disease and AIDS has been influenced by a number of factors, some of which are unique to California, while others are shared by all states. Among the factors influencing California's response, the following five are most notable.

First, California is large and diverse—a place of great

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ABBREVIATIONS USED IN TEXT
AIDS = acquired immunodeficiency syndrome
CDHS = California Department of Health Services
HIV = human immunodeficiency virus

contrasts. It is the third largest state in the nation, encompassing more than 158,000 sq mi. It is also the most populous state, with more than 28 million people. This population is not evenly distributed, however; California contains some of the most densely and most sparsely populated areas in the world. It is also the most environmentally diverse, possessing large wilderness areas, two major deserts, immense tracts of agricultural land, seven distinct mountain ranges, 1,770 km (1,100 mi) of coastline, and both the highest and lowest points on the continental United States. Further, it is the most ethnically diverse state in the country, with commensurate heterogeneity of life-style. It is similarly heterogeneous with regard to human service resources, exemplified by the physician-to-population ratio, which ranges from nearly twice the national average in parts of the San Francisco Bay Area to one county that does not have a single resident physician. With 61 local health jurisdictions, some large or reporting many AIDS cases and others small or with no reported AIDS cases, each of these jurisdictions has experienced the impact of the HIV epidemic differently. To date, about two thirds of California's AIDS cases have been reported from San Francisco and Los Angeles counties.[4]

Second, knowledge about the pathophysiology, natural history, prevention, and treatment of HIV disease has developed rapidly, especially in the first five years of the epidemic. More has been learned about HIV disease in a shorter time than about virtually any other disease in history. Consequently, the state's approach to the epidemic has had to be flexible enough to accommodate and apply the latest information and scientific developments as they have been discovered.

Third, since first being recognized, HIV disease has affected certain communities and certain groups more than others. Some communities—San Francisco, for instance—have experienced a substantial impact, while others have yet to see their first case. While no community in California will escape the effects of the epidemic in the future, this historically important and continuing disproportionate impact has affected statewide efforts and is a reason why local planning, within the context of overall state guidance, is so important.

Fourth, in addition to its medical and public health considerations, HIV disease entails a number of sociopolitical issues about which there are wide-ranging opinions. Indeed, there has never been a disease in which health considerations have been so intertwined with issues of personal morality and sexuality; social issues of race, class, and family; philosophic concerns about individual and social responsibility; and matters of politics and economics. Again, this complicates statewide planning for the epidemic and underscores the need for local jurisdictions to tailor approaches to the disease to the circumstances of their individual communities.

Fifth, the complexities of HIV disease and the size and diversity of California make it clear that no one approach or strategy will adequately address the needs of HIV disease prevention and treatment programs in this state. Considering the disparate nature of the groups of people who have been infected with the disease and the varying nature of the communities in which these persons live, it is clear that a multifaceted and multidimensional approach to the disease must be undertaken.

Given these difficulties, it is imperative that each local health jurisdiction, using the latest information available, develop its own plan for the prevention and treatment of HIV disease in ways best suited to its citizens.

California's Approach to the HIV Epidemic

To combat the HIV epidemic within the above context, California has developed a five-point approach based on sound medical and public health principles. This strategy has been designed to be flexible enough to accommodate the changing nature of the epidemic and the great diversity of California, as well as to be sensitive to the concerns, fears, and sensibilities of all Californians.

The five-point California approach to the HIV epidemic entails the following components:

- Epidemiologic surveillance;
- Prevention education;
- Provision of medical treatment and supportive services;
- Research; and
- Continuous planning, evaluation, and coordination of programs.

Epidemiologic surveillance has included such activities as establishing an AIDS reporting system (the AIDS Registry) in March 1983, implementing the Alternative Test Site program, ascertaining HIV seropositivity among blood donors, and completing special seroprevalence studies.[5,6] A number of other activities in this regard currently are under way, and additional studies are planned for the future.

Prevention education has been our highest priority in the battle against HIV disease and will remain the focal point of our arsenal because neither a cure nor a vaccine for HIV infection is likely to be developed in the near future. Indeed, 29% of the $77.1 million appropriated to CDHS for AIDS in the past five years has been for prevention education. Overall, from fiscal year 1983-1984 through 1987-1988, California has appropriated a total of $117 million in state funds for the fight against HIV disease.

Specific prevention education activities have included providing funding for nonprofit community-based organizations and local health departments to conduct HIV disease prevention education programs, targeting special educational efforts at alternative test sites, developing various educational instruments for selected groups and the general public, and conducting a statewide AIDS education campaign.[7-10]

Activities undertaken with regard to medical treatment and supportive services include providing care through the Medi-Cal and California Children Services programs, as well as county health service programs[11-13]; initiating nearly 30 home health and attendant care pilot projects; submitting an application for a home and community-based care waiver to the federal Health Care Financing Administration; developing regulations to provide services in hospices[14]; pursuing legislation to establish a new category of licensed health care facility for persons with AIDS; and initiating or collaborating on various HIV disease cost-of-care studies.

The California state government approach to AIDS research has been unique in the nation. It has included the

generous support of research through the University of California and other academic institutions, implementing an HIV vaccine development program, a state-only effort to expeditiously make available new drugs for AIDS treatment, and providing funding for a special HIV disease research institute at San Francisco General Hospital and Medical Center.

Finally, while less tangible than the other elements of the state's HIV disease control strategy, evaluating and coordinating programs are just as important as the other components and are identified separately in our strategy to highlight their importance. To assist in this regard, CDHS has convened various advisory groups and task forces, including a state AIDS leadership committee.

While much has been done at the state level, it is anticipated that additional issues and programs will need to be developed in the future. We think, however, that these need to be developed and implemented within the context of local planning. Such combined state and local efforts are imperative in light of the fact that there is no quick solution to the HIV epidemic—that is, HIV disease prevention and treatment programs must be designed for the long term. These efforts must be flexible and capable of changing quickly as new data emerge. It is also important to note that because HIV transmission involves sexual activity and the use of illegal drugs, it is inevitable that some persons will be offended by certain aspects of HIV disease prevention and treatment programs. Clearly, programs should be designed to offend as few people as possible, but it is not realistic to expect that effective intervention programs for this disease can be implemented and not displease some persons.

In an effort to meet the challenges presented by the HIV epidemic, the CDHS has proposed a framework for local AIDS prevention and treatment program planning, with the goal that local health jurisdictions will develop plans that use most effectively the prevention and treatment resources available in their communities.[1] Such efforts will facilitate state planning, especially by identifying statewide needs and special needs existing within local jurisdictions. The purpose of the proposed framework is to identify those areas in which particular attention should be focused by the local jurisdiction. To do this, we have delineated the fundamental elements that should go into local plans and describe what we think should be the role of state government, realizing that both local and state plans are meant to be living frameworks that, although designed for the long term, will nevertheless evolve over time.

The Role of the California Department of Health Services

Local planning for the prevention and treatment of HIV disease in California should be pursued with an understanding of the role of the California Department of Health Services because CDHS has been designated as the lead agency for AIDS-related matters for California state government. A similar designation to the state health department has been made in most other states.

Although the role of the state health department is in many ways similar to that of a local health department, in other ways it is unique to state government. The various roles of CDHS are briefly summarized in Table 1. While other state health departments share many of these same roles, individual state differences exist; in such cases, this model can be modified accordingly.

TABLE 1.—*Role of the California Department of Health Services in HIV Disease Planning and Program Implementation*

Help establish general state policy
Promulgate overall state goals and program guidelines
Facilitate the efforts of local, state, and federal agencies
Serve as a convening authority
Provide technical assistance, including the review and approval of local plans
Operate and monitor statewide programs
Obtain, dispense, and coordinate state and federal funding
Initiate and conduct or oversee special studies
Collate and disseminate information

HIV=human immunodeficiency virus

The primary responsibility of CDHS, in consultation with the California AIDS Leadership Committee and other relevant groups, is to help establish general state policy and overall state goals and program guidelines for the prevention and treatment of HIV disease. Further, the role of CDHS is to guide, consult with, and support local health jurisdictions to ensure that the most advanced and effective HIV disease prevention and treatment programs are functioning throughout the state. CDHS—and its Office of AIDS in particular—will provide technical and other assistance to local jurisdictions in formulating plans for HIV disease prevention and treatment programs. Insofar as it is possible, CDHS will maintain and make available a team of experts in each program element—epidemiologic surveillance, HIV antibody testing, prevention education, medical treatment and supportive services, and health care financing mechanisms—to assist local jurisdictions in developing plans and implementing programs. Field staff will be available to assist local personnel on a day-to-day basis.

Although there are no current statutory requirements for state review and approval of local HIV disease plans in California, it is thought that the best allocation and the most effective use of state funds can be made by ensuring that each local jurisdiction has an appropriate HIV disease prevention and treatment plan that is consistent with overall state goals and priorities and that state funding be tied to the plan.

CDHS also has responsibility for implementing, operating, and monitoring various statewide programs and activities. Such activities include the California AIDS Reporting System, the Alternative Test Site program, and blood bank surveillance. CDHS also is responsible for securing Medicaid waivers from the federal Health Care Financing Administration; developing and piloting innovative programs; preparing statewide reports for the California legislature and federal agencies; responding to federal requests for California data; applying for federal grants; convening special workshops, conferences, or other such forums; collating and disseminating information to local jurisdictions; initiating, conducting, and overseeing various HIV disease-related studies; and allocating and coordinating state and federal funding for HIV disease programs.

One of the anticipated benefits of coordinated state and local HIV disease planning is the opportunity to provide needed flexibility in funding for local activities. For various reasons, state funding for AIDS programs in California has been accompanied by specific budget-control language *in*

past years. This has limited both state and local flexibility in using these funds and has required considerable administrative work in managing contracts and similar processes. This budgetary specificity has resulted in delay in transmitting state funds to local groups and has generated an undesirable amount of bureaucratic work.

Ideally, the state and local funding mechanism would involve the least necessary administrative work; provide necessary accountability, both programmatically and fiscally; permit flexibility and local discretion so that maximum effectiveness would accrue from the use of the limited funds; and stipulate the responsibilities and duties expected and required for each level of government. Obviously, state and federal funds should be distributed to local jurisdictions in accordance with established priorities and overall state and national goals. To ensure that these characteristics of the funding mechanism are met, it is important that local plans provide sufficient detail so that needs can be accurately assessed and that program implementation, management, and evaluation procedures can be assessed.

Developing Local Plans

The California Department of Health Services recommends that each local health jurisdiction develop a three-year HIV disease prevention and treatment plan, realizing that the plan will most assuredly require subsequent modification to accommodate changing circumstances and new data.

An integral part of the local HIV disease plan and a requisite first step are assessing present needs and resources, along with projecting how those needs and resources are likely to change over the ensuing three years.

There are five essential components of a local HIV disease prevention and treatment program that need to be addressed by a local plan:

- Central participatory planning,
- Prevention and testing programs,
- Epidemiologic surveillance,
- Providing treatment and supportive services,
- Coordinating financing mechanisms.

These major program elements and goals are considered minimum requirements. Specifying only these elements should not discourage local jurisdictions from going beyond these basic requirements or lead them to believe that these are all that need to be addressed when circumstances indicate the need for a broader approach or a more detailed plan. Likewise, the focus on local plans should not be construed as discouraging regional approaches to HIV disease prevention and treatment. To the contrary, regional planning is strongly encouraged.

Central Participatory Planning

Key to developing any local HIV disease prevention and treatment plan is the establishment of a local advisory body that can assist and guide local program development and implementation. This body should comprise persons with HIV disease-related expertise and other relevant experience in planning and decision making. Membership should be representative of the various groups affected by HIV disease, including persons with HIV infection and providers of services, as well as community-based organizations involved with HIV disease. A coordinator or team leader should be selected to manage the local program and to coordinate the various local government, private, and community-based organizations involved in HIV disease prevention and treatment. A mechanism should be in place that assures this person immediate access to relevant medical and public health advice.

In California, the state level advisory function has evolved through several iterations. At present, this need is being met by the California AIDS Leadership Committee, a group of more than 30 knowledgeable persons from various backgrounds, that reports to the CDHS.

Prevention and Testing Programs

Simply put, HIV disease prevention programs are directed at interrupting the transmission of HIV. HIV antibody testing is a useful element in the prevention program when the testing is combined with personal education or counseling that, when appropriate, leads to behavior modification. Guidelines for HIV antibody testing in California have been promulgated by CDHS,[15] as have guidelines for HIV partner notification programs.[16] Among the activities that should be included here are the following:

- Preventive education programs designed to effect behavior change in persons engaging in activities known to promote the transmission of HIV. These programs likely will include general public education through the media, schools, worksites, and community service organizations; outreach and targeted education for gay and bisexual men, intravenous drug users, prostitutes, homeless persons, and other persons at high risk; special HIV antibody testing and educational programs for local sexually transmitted disease clinics, drug detoxification and methadone treatment programs, family planning clinics, prenatal care clinics, correctional center medical facilities, and partner notification programs; and medical facility-based HIV antibody testing and prevention education programs for hemophiliacs, blood transfusion recipients, perinatal patients, and hospital workers, among others.
- Prevention education and medical treatment programs for presymptomatic evaluation, monitoring, and prophylactic therapy for HIV-infected persons.
- A means of evaluating local changes in high-risk behavior, the incidence of sexually transmitted diseases, HIV seroprevalence changes, and program outcome.
- Screening of donors of blood and blood products, tissues, and organs.
- Perinatal intervention programs, including screening and counseling at prenatal and family planning clinics.

The prevention plan needs to involve local community-based organizations and especially those organizations that have an established record of activity in this regard. These programs need to be coordinated and integrated into the overall local plan.

Epidemiologic Surveillance

Establishing an appropriate local HIV disease policy and plan depends on knowing the extent, pattern, and trend of HIV infection in the local jurisdiction as well as statewide and nationwide. Thus, the local HIV disease prevention and treatment program must include a means of epidemiologic surveillance to determine and monitor the local incidence and prevalence of HIV infection and on which to base current and future caseload and needs projections.

Treatment and Supportive Services

Local HIV disease plans should specifically address the various medical treatment and supportive service resources of the area to assure access to adequate health care for all persons with HIV infection. In this regard, the local plan should consider the expected patient caseload relative to geography, risk group, ethnicity, and other relevant factors. It should also estimate the present and future resources required to provide care for HIV-infected persons, projected shortfalls in resources, and means by which anticipated shortfalls can be addressed.

Ideally, persons with HIV infection should be "case managed" so that the provision of medical treatment and social support services is coordinated within a comprehensive system of health care.

Among the specific treatment resources that should be considered and arranged for are the following:

- Serologic HIV antibody screening—both anonymous and confidential;
- Presymptomatic evaluation, monitoring, and prophylactic therapy for HIV-infected persons;
- Inpatient care for persons with acute HIV-related illness;
- Extended care for symptomatic persons not needing acute inpatient care, including skilled nursing, home health, and residential care;
- Hospice care; and
- Mental health and support services, including situational counseling, acute psychiatric care, and long-term care for HIV dementia.

In addition to the above, the local plan should include mechanisms to address legal issues related to human rights, discrimination, patient privacy, mandated testing, patient isolation, and civil commitment because these are likely to arise. And while civil liberties are not traditionally a focus of health planning, such issues are so intimately associated with HIV disease that a means to address them should be viewed as a key component of any HIV disease prevention and treatment plan.

Coordinating Financing Mechanisms

The financing of HIV disease prevention and treatment services involves a mix of public and private funds, from both local and distant sources. Insofar as public funds may originate from multiple local, state, and federal agencies, it is essential that a mechanism exist for coordinating the various financing mechanisms. Likewise, a means needs to exist whereby funds can be rapidly distributed to local entities while maintaining the requisite programmatic and fiscal accountability.

In the same vein, a means to evaluate the cost-effectiveness of the various HIV disease prevention and treatment components is essential to ensure continued support of these programs.

Conclusion

As health care practitioners, public health professionals, and policymakers, we are challenged to develop effective HIV disease prevention and treatment programs that are comprehensive yet flexible enough to accommodate the resource, caseload, cultural, and sociopolitical diversity of California. We think the model presented here will be helpful in that regard.

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